

## BRIEF COMMUNICATION

# Testing awareness in focal seizures: Clinical practice and interpretation of current guidelines

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## Abstract

The International League Against Epilepsy (ILAE) classification of focal seizures uses recall of experiences post-ictally to assess for awareness and not ictal responsiveness to external stimuli, stating that responsiveness is often not tested. We investigated how clinicians assess for seizure awareness by administering an online survey. We found that most respondents use both responsiveness and recall to assess for awareness in the clinic (78%) and in the epilepsy monitoring unit (72%). Furthermore, 60% of respondents believe that the ILAE recommends using both measures. Given our results, we believe that using both responsiveness and recall would provide a more practical classification of impaired consciousness in focal seizures.

## Introduction

Epilepsy is a common neurological disorder, with a worldwide point prevalence of active epilepsy of 6.38 per 1000 persons and a lifetime prevalence of 7.60 per 1000 persons.<sup>1</sup> While there are different types of seizures that lead to different neurological manifestations, a major concern for both patients and providers is if consciousness is spared or impaired. This is an important aspect of seizures to consider when clinicians make recommendations for their patients, especially regarding driving safety and other life-altering events when seizures are not well controlled.<sup>2</sup> As such, determining if consciousness is impaired ictally becomes critical for clinical providers. While “consciousness” might be difficult to define, the International League Against Epilepsy (ILAE) states that “awareness” can be used as a proxy.<sup>3,4</sup>

Given the clinical importance of awareness during seizures, it is worth investigating how clinicians assess it.

One method to assess for ictal awareness is ictal responsiveness, in which clinicians ask patients to respond to a stimulus during their seizure. Another method is recall of experiences, in which patients are asked post-ictally to recall ictal events. In classifying focal seizures, the ILAE recommends using only recall of experiences during seizures to assess for awareness, and not responsiveness, because patients may be aware but unable to respond due to behavioral arrest. In addition, the ILAE states that ictal responsiveness is not often tested, citing this as another reason to avoid using responsiveness in testing for ictal awareness.<sup>3</sup> While the listed limitations of responsiveness testing are true, recall testing has limitations as well. For example, it is possible that patients are aware during their seizures but are unable to recall it after, given that focal seizures have been associated with transient amnesia.<sup>5,6</sup> Therefore, we decided to investigate how clinical providers across multiple institutions assess for awareness in

epilepsy, as well as their understanding of ILAE guidelines, as this has implications for future epilepsy clinical recommendations and classifications.

## Methods

Our study was approved by our human subject institutional review board and appropriate consent was obtained. In 2021 we emailed clinical providers across 11 medical institutions and asked for our anonymous survey to be distributed to their epilepsy emailing groups. Both adult and pediatric epilepsy programs were included. The email included the subject line “Brief Questionnaire on Focal Aware and Focal Impaired Awareness Seizures,” mentioned that the survey was anonymous, and provided a link to a Qualtrics survey tool. Responses to the survey tapered off quickly after the initial emails and the survey was closed after 2 months. The survey included a total of eight questions (Table S1). We asked participants two questions about how they assess awareness during focal seizures in their clinical practice—one question about their clinic and the other about their institutions’ epilepsy monitoring unit (EMU). We asked participants if they assess awareness based on the ability of the person having the seizure to later recall events occurring during the seizure, based on the ability of the person having the seizure to respond to external stimuli during the seizure, both measures, or neither. We also asked participants which of these measures they believe the ILAE recommends for assessing awareness during seizures. Finally, we asked participants five demographic questions, including sex, race/ethnicity, how long they have been practicing medicine, what type of clinical practice they work in (adult vs. pediatric, epilepsy vs. non-epilepsy), and what their clinical setting is like (academic, non-academic, rural, suburban, urban). The survey questions can be found in Table S1. We analyzed the data using Excel and SPSS, and analyzed proportions by paired chi-squared tests with significance threshold of  $p < 0.05$  (Bonferroni-corrected as appropriate for multiple comparisons).

## Results

We obtained a total of 58 completed survey responses. One additional survey was submitted but it was blank, and therefore, was excluded from analysis. The demographics of the respondents are listed in Table 1. We discovered 78% of the respondents stated that they use both responsiveness and recall testing to assess awareness when classifying focal seizures in their clinic, and this was significantly greater than the 16% of responses using only recall measures ( $p < 0.001$ , chi-squared test) as well as the 5% of responses using only responsiveness measures ( $p < 0.001$ , chi-squared

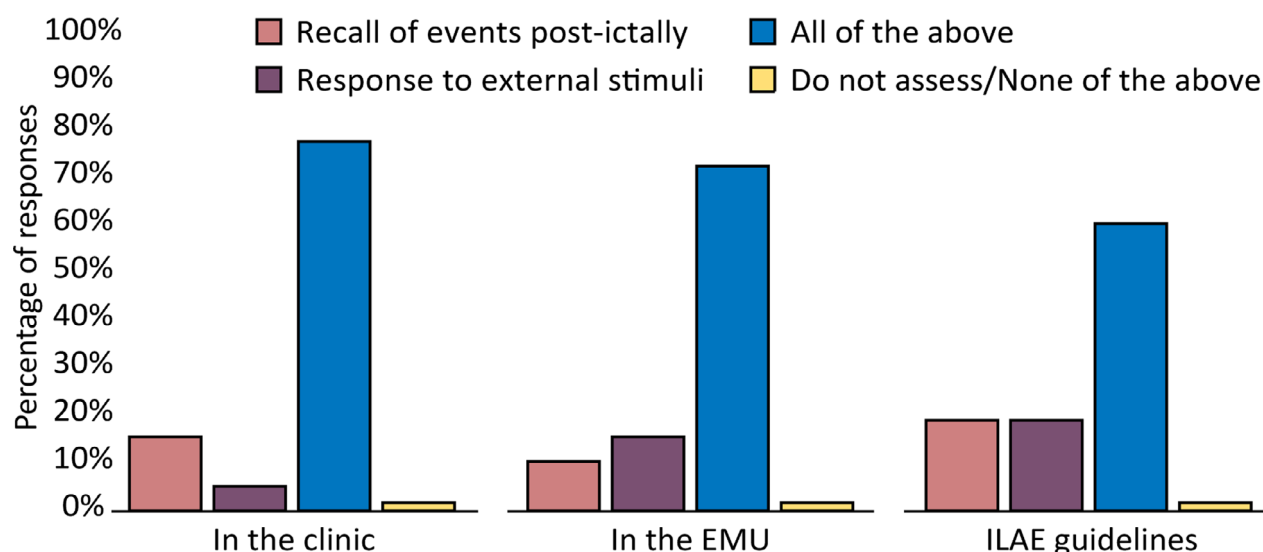
**Table 1.** Demographics.

Category	Number	Percentage (%)
Sex		
Female	20	34.5
Male	34	58.6
Other	0	0
Prefer not to answer	4	6.9
Race/ethnicity		
White	34	58.6
Black	1	1.7
Hispanic/Latino	3	5.2
Asian	13	22.4
Native American	0	0
Pacific Islander	0	0
Other	3	5.2
Prefer not to answer	4	6.9
Duration of medical practice		
Still in training	11	19.0
Finished training <5 years ago	10	17.2
Finished training between 5 and 15 years ago	19	32.8
Finished training more than 15 years ago	18	31.0
Main clinical practice		
Adult non-epilepsy	4	6.9
Adult epilepsy	38	65.5
Pediatric non-epilepsy	0	0
Pediatric epilepsy	13	22.4
Other (imaging, neurosurgery, psychiatry)	3	5.2
Main clinical practice setting (select all that apply)		
Non-academic neurology	1	1.7
Academic neurology	53	91.4
Rural	0	0
Suburban	1	1.7
Urban	6	10.3

Study participant demographics obtained from survey.

test) (Fig. 1). Similarly, 72% of respondents stated that their EMU uses both responsiveness and recall measures to assess awareness, which was significantly greater than the 10% of respondents stating that their EMU uses only recall measures ( $p < 0.001$ , chi-squared test) or 16% stating that only responsiveness measures were used ( $p < 0.001$ , chi-squared test) (Fig. 1). Finally, 60% of respondents believe that the ILAE recommends using both responsiveness and recall measures, which is greater than the 19% of respondents who believe it recommends using only recall measures ( $p < 0.001$ , chi-squared test) or the 19% who believe it uses only responsiveness measures ( $p < 0.001$ , chi-squared test) (Fig. 1).

More of the participants were male than female, the majority were White or Asian, and the vast majority were in adult or pediatric epilepsy practice in an academic



**Figure 1.** Responses to questionnaire. Participant responses to questions about how they assess for ictal awareness in the clinic, how they assess for ictal awareness in the epilepsy monitoring unit (EMU), and about their understanding of the International League Against Epilepsy (ILAE) guidelines for assessment of awareness during seizures. Data are from 58 survey respondents at 11 epilepsy centers.

setting (Table 1). Of the demographic factors measured, we hypothesized that type of clinical practice, and practice duration (recency of training) might influence familiarity with the ILAE guidelines and therefore the survey responses. However, multinomial logistic regressions showed that there were no significant associations between the type of clinical practice or practice duration and the responses to the questions about how clinicians assess for conscious awareness in the clinic ( $p = 0.28$  and  $p = 0.41$ , respectively), in the EMU ( $p = 0.26$  and  $p = 0.42$ , respectively), or their understanding of ILAE guidelines ( $p = 0.32$  and  $p = 0.64$ , respectively).

## Discussion

Our survey results indicate that most participants use both patients' ictal responsiveness and post-ictal recall of experiences to assess awareness when classifying focal seizures. Interestingly, most participants also erroneously believe that the ILAE guidelines recommend using both measures to assess awareness. This contradicts the ILAE's statement that responsiveness measures are not often used to assess for conscious awareness.<sup>3</sup>

A limitation of our study is that most participants were academic clinicians, many of whom have access to EMUs. Because EMUs allow for seizure detection in real time, clinicians in this setting may be biased to include responsiveness as a measure of awareness during seizures. This may not generalize to the whole population of clinicians, because those who work mainly in the outpatient setting may rely more on reported recall of events during

seizures. Nevertheless, many of the participants stated using responsiveness and recall not only in the EMU, but also in the outpatient setting as well. Furthermore, ILAE guidelines are meant to be useful in all settings throughout the world. However, the current results suggest that the same type of practitioners—namely academic neurologists and epileptologists—who devised the ILAE criteria for classifying focal seizures, do not correctly use these criteria in their practice. Another limitation is the order of the questions in the survey. We first asked participants how they assess for awareness during seizures in their clinic and in the EMU, followed by the question about ILAE guidelines. Therefore, it is possible that participants' responses about their practice influenced how they replied to the question about guidelines, overestimating their lack of knowledge of the guidelines. Future surveys on this topic should present the questions in random order to avoid this potential source of bias.

We acknowledge that clinical setting may dictate how conscious awareness during seizures is measured. While some clinicians may consider classifying seizures in an EMU to be the gold standard, second-hand accounts either by patients or witnesses are also clearly very valuable. Outside of the EMU setting, it is rare for clinicians to witness patients' seizures and therefore, relying on reports by external witnesses or on patient self-reports is vital to clinical care. Recent research indicates that self-reports may agree with external observers for some seizure characteristics, especially memory ability during seizures.<sup>7,8</sup> On the other hand, patients often underreport the occurrence of seizures, likely also limiting their ability

to report on seizure characteristics,<sup>8,9</sup> and many seizures are unwitnessed particularly in sleep. For seizure classification, ideally all information should be used from witnesses, self-report, and direct observation from the EMU when available.

Given that an accurate understanding of a patient's awareness during seizures is vital to providing adequate clinical recommendations, it is important to understand how awareness is assessed. While our study did not specifically compare the accuracy of using responsiveness versus recall testing, we are aware of possible limitations when only one method is used. Using only recall of events post-ictally, as recommended by the ILAE, may not accurately classify seizures in which patients suffer from post-ictal amnesia despite being aware during their seizure. Conversely, using only responsiveness during seizures may misclassify seizures in which patients cannot respond during the seizure due to behavioral arrest despite being consciously aware. Future work should quantify how often impaired responsiveness and recall are concordant or discordant in different seizure types. Given the limitations of either method in isolation, and the fact that many clinical providers report using both methods simultaneously, we believe that using both methods together will lead to a more accurate and useful classification of conscious awareness during seizures.

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## Conflict of Interest

None of the authors have any conflict of interest to disclose.

## Author Contributions

Violeta Contreras Ramirez contributed to the design of the study, including the development of the survey, data analysis, and manuscript writing. Aparna Vaddiparti

contributed to the design of the study and development of the survey. Hal Blumenfeld contributed to the design of the study, development of the survey, and editing manuscript.

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## Supporting Information

Additional supporting information may be found online in the Supporting Information section at the end of the article.

**Table S1.** Survey sent to practitioners, including questions and response options.